

## PROJECT IDENTIFICATION

Project Title: Pediatric/Adolescent Blood Disorders Program

Project Number: 1 H46 MC 00163-01

Project Director: Krystal Bottom, M.D.

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Grantee Organization: Mission St. Joseph's Health System

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Project Period: 9/1/99 – 5/31/03

Total Amount of Grant Awarded: \$525,000

## FINAL REPORT

### NARRATIVE

I. PURPOSE OF PROJECT AND RELATIONSHIP TO SSA TITLE V MATERNAL AND CHILD HEALTH (MCH) PROGRAMS: Prior to the inception of this grant, there were no local systems of care for children in Region I of the NC Sickle Cell Syndrome Program. Region I includes 24 counties and covers over 8,000 square miles in Western North Carolina. The mountainous topography of this region leaves certain areas isolated and encumbers the necessary travel to health care facilities that chronic health conditions require. Families of children with sickle cell hemoglobinopathies were traveling 2 to 6 hours from their homes to seek specialized medical and psychosocial care.

II. GOALS AND OBJECTIVES: The overall goal for the Pediatric/Adolescent Blood Disorders Program (PABDP) was to address the unmet medical and psychosocial needs of the patients and families involved, and to provide services within the families' community. Related goals included: improving the health of children living with sickle cell disease and other inherited blood disorders, increasing the knowledge and understanding of sickle cell disease and other inherited blood disorders in Western North Carolina, and ensuring continuity of care for all patients in the program.

*The objectives for the program were as follows:*

- 1.) conduct a needs assessment identifying the distribution of genetic hematological conditions in Western North Carolina
- 2.) enroll 95% of all referred children in Western North Carolina identified with abnormal hemoglobin to the Pediatric/Adolescent Blood Disorders Program
- 3.) enroll 30 children presently identified with a hemoglobinopathy into the program by December 30, 2000
- 4.) ensure that 100% of participants have a health and preventive care plan
- 5.) develop 24-hour comprehensive ambulatory outpatient and inpatient care for patients with sickle cell syndromes and other inherited hematologic disorders
- 6.) develop a comprehensive continuous care plan from birth through transition into an adult medical home
- 7.) establish a culturally competent and comprehensive resource center
- 8.) establish a centralized regional data center to track infants, children, and adolescents with sickle cell syndrome or other hematological disorders

9.) develop satellite clinics in identified areas within the Western North Carolina region, in response to patient population and need

III. METHODOLOGY: Objective 1 was to conduct a needs assessment identifying the distribution of genetic hematologic conditions in the following populations: African-American, Mediterranean, Asian, Northern European, Middle Eastern, Hispanic and Native American (Activities 1.1-1.3); assessing the current status of care (Activity 1.4); and determining dental care availability (Activity 1.5).

*Progress Made:*

(Activities 1.1-1.3) In ongoing conversations with the NC Sickle Cell Syndrome Program Director, Daisy Morris, and Maternal Health Unit Supervisor, Belinda Pettiford, PABDP addressed the need to be established as a reporting site for Region I NC newborn screening results. The referral pattern of patients with hemoglobinopathies to PABDP was inconsistent. In addition, PABDP worked on clarifying data-sharing agreements that would assist in the achievement of these activities. A research assistant was hired in December 2000, and also worked on these issues.

(Activity 1.4) This information was obtained on a case-by-case basis with patients within the program, through the use of patient surveys developed by the research assistant. The research assistant plans to have this completed by May 2003, pending appropriate response sets.

(Activity 1.5) This information was also obtained on a case-by-case basis. Referrals to appropriate dental care services were made as needed.

Objective 2 was to enroll 95% of all referred children in Western North Carolina identified with abnormal hemoglobin into the program by September 30, 2000 by:

establishing a regional center for early and rapid response to the identification of a newborn with an abnormal hemoglobin (Activity 2.1); establishing a communication link with the NC State Newborn Screening Program for regional identification of at-risk newborns and redundant mechanism to follow up primary care physician notification of a child with an abnormal hemoglobin (Activity 2.2); establishing a regional physician and interstate communication center to identify and test, if indicated, children born outside NC, or prior to 1994 (Activity 2.3); and to increase community awareness of hematologic disorders through community health programs specifically aimed at educating the public about these disorders (Activity 2.4).

*Progress Made:*

(Activity 2.1) PABDP was established as a comprehensive sickle cell center for Region I. There was an increase in the referral pattern from regional physicians and health care providers as more inservice programs were provided by PABDP.

(Activity 2.2) The distribution of newborn screening results included the pediatrician/primary care provider, the Region I Educator/Counselor for the NC Sickle Cell Syndrome Program (this position is currently vacant, however), and the parents of the child positive for a hemoglobinopathy. This system continued to present problems for long term follow-up. A major ongoing barrier to an early and rapid response was the lack of consistent referrals to PABDP from the Region I Educator/Counselor for the NC Sickle Cell Syndrome Program. This issue was continuously addressed, and PABDP worked with state officials on possible solutions for this issue. A new person is being hired for this position, and it is hoped that will assist with the referral process.

(Activity 2.3) On a case by case basis, PABDP tested children born outside of North Carolina and also any children born prior to 1994 who were at risk for hemoglobinopathies, or who requested testing. PABDP also screened other family members, including parents and siblings, to rule out any abnormal hemoglobin lab results. This was helpful in the ongoing genetic counseling that PABDP staff did with the families.

(Activity 2.4) PABDP staff provided educational opportunities to regional health care providers on hematologic disorders, and also provided community health programs to area providers and community groups at their request.

Objective 3 was to enroll 30 children identified with a hemoglobinopathy into the program by December 30, 2000 by: conducting a needs assessment to identify the number of such children (Activity 3.1); contacting families of those identified (Activity 3.2); and recruiting them into program (Activity 3.3).

*Progress Made:*

(Activities 3.1, 3.3) The program had 16 identified patients in February 2000. A Master's prepared Social Worker, Amy Niemas, was hired in April 2000. A new Project Director, Susan Maulsby, was hired in October 2000. At that time, PABDP had grown to 30 patients. The program continued to expand, and at the time of this writing, there were 61 patients with a hemoglobinopathy enrolled in the program. This includes patients with sickle cell trait. The NC Sickle Cell Syndrome Program has recently stressed the importance of ongoing care for patients with sickle cell trait, and this is also being emphasized at the national level. There were an additional 65 patients with a genetic blood disorder (such as hemophilia, von Willebrand's, spherocytosis, and Factor V

deficiencies), who were also case-managed by PABDP staff. This brought the total number of patients to 126. Referrals came primarily from local pediatricians' offices. This demonstrated a dramatic increase in program growth, despite the major barriers in consistent referral patterns previously mentioned. PABDP also worked with state officials to expand the growth of the program, so that all children with hemoglobinopathies had access to health care. PABDP specifically recognized issues surrounding the recruitment and retention of the Asian/Hmong population into the program, and worked towards overcoming this barrier. However, there was limited success in this effort, due to cultural issues (i.e., avoidance of Western health care institutions) and demographic distribution.

(Activities 3.2-3.3) Contact with families was done on a case by case basis. The families were receptive to this contact, and expressed relief numerous times in having accurate and complete information and follow-up by PABDP staff.

Objective 4 was to ensure 100% of participants have a health and preventive care plan by December 30, 2000 by: providing a case worker or workers, as needed, for this population to insure timely communications as well as educational material and instruction, as needed, to insure optimal health status, minimize hospital or emergency department visits, and improve quality of life (Activity 4.1); develop a medical/paramedical team to review disease complications and patient adherence with prescribed medical and preventive care plan (Activity 4.2); complete a comprehensive work up that includes a family study, at-risk information, training, and genetic counseling (Activity 4.3); collaborate with middle and high school nurse-managed clinics in the region, integrating them into the health team for children with potential medical complications

associated with inherited hematological disorders and encourage and promote expansion of school nursing programs into school districts without school nursing services (Activity 4.4); and initiate an educational program about inherited diseases and their associated physical, emotional, and medical complications to middle and high school students through health classes (Activity 4.5).

*Progress Made:*

(Activity 4.1) PABDP was staffed with 2 physicians, 1 RN/Project Director, and 1 MSW. One of the physicians, Dr. Krystal Bottom, took the lead role in providing the medical direction for the program. The RN/Project Director and the MSW were responsible for implementing the grant objectives under Dr. Bottom's guidance. Other staff (e.g., hematology/oncology nurses, nutritionists, physical therapists, child life specialists, chaplains, and school health nurses) were utilized to provide comprehensive care to each patient and family. Quarterly reports assessing ER and hospital utilization were completed and provided to the state as required.

(Activity 4.2) The multidisciplinary team was scheduled to meet once a week to discuss issues regarding patients within the hematology/oncology program, to review recent research findings, and to share information gathered from any conferences, workshops, or continuing education units. The Medical Director, RN/ Project Director, and MSW also met regularly to discuss issues specific to the blood disorder patients.

(Activity 4.3) This activity was designated to the Region I Sickle Cell Educator/Counselor, but PABDP received minimal amounts of that information. Therefore, PABDP staff completed this work for each of the patients and families in the program and updated it as needed.

(Activity 4.4) PABDP staff made numerous visits to schools in the region and collaborated with area school nurses and staff to coordinate care for the patients.

(Activity 4.5) An educational program was developed by PABDP staff, for use in the school setting. PABDP staff expanded this objective to include materials for all schools (i.e., daycares, primary schools, and elementary schools, not just middle and high schools). Education was provided to each patient and family in the program.

Objective 5 was to develop 24-hour comprehensive ambulatory outpatient and inpatient care for patients with sickle cell and other inherited hematologic conditions by September 30, 2000 by: maintaining an ambulatory outpatient facility staffed with RNs trained in hematological disorders of children, and a board-certified Pediatric Hematologist from 8:00am to 6:00pm (Activity 5.1); providing a Pediatric Hematologist and Pediatric Emergency Medicine subspecialist to the ER from the hours of 6:00pm to 8:00am to complete the 24- hour comprehensive care plan (Activity 5.2); establishing a Patient and Family Services Program for children with sickle cell syndromes and inherited hematologic disorders, their siblings and parents, to facilitate education, family support, peer support, patient transportation, and financial assistance (Activity 5.3); expanding the Pediatric Chaplaincy Program to include hospitalized children with complications of inherited hematological disorders (Activity 5.4); including nutritional assessment and interval assessments by a Registered Dietitian to maintain appropriate nutritional status for developmental stage (Activity 5.5); including physical therapy evaluations and treatment for those with skeletomuscular complications from sickle cell syndrome crisis (Activity 5.6); providing developmental evaluations as needed/indicated (Activity 5.7); and developing a 24-hour 1-800# phone triage service with expertise in hematologic

disorders for referring physicians and regional Emergency Departments, including access by patients and their families with questions about complications associated with inherited hematological disorders or acute and non-acute referrals (Activity 5.8).

Objective 5 describes the comprehensive services offered to patients of the Pediatric/Adolescent Blood Disorders Program. Patients requiring acute care were admitted to the general Pediatric Unit, the Pediatric ICU, or the Pediatric/Adolescent Surgical Unit.

*Progress Made:*

(Activity 5.1) PABDP patients were seen on an outpatient basis at the Pediatric Outpatient Unit (POP). The POP Unit is staffed by RN's with specialty training, and in most cases, certification in Pediatric Oncology/Hematology Nursing. One of two Board-Certified Hematologists is on site in the unit Monday through Friday between 8:00am and 6:00 pm. The support staff for POP includes two child life specialists.

(Activity 5.2) The two Hematologists serving as PI's on this project rotate call every other week, thus providing 24-hour coverage by a Board-Certified Hematologist.

(Activity 5.3) Amy Niemas, MSW attended various conferences to aid in the development of a Patient and Family Services Program, including specific topics relating to cultural diversity issues. Patients and families received ongoing psychosocial support and education during clinic visits, inpatient stays, via telephone, and during home visits. A support group for parents of children with blood disorders was established in January 2001. Issues of patient transportation and financial assistance were addressed on a case by case basis with the resources available to the program. Due to the limited funds available for patients and families, PABDP staff worked in conjunction with the MSJ

Foundation to establish an emergency funds program specifically for the patients and families enrolled in the program.

(Activity 5.4) A Pediatric Chaplain, Sherry Morrow, was hired for Mission St. Joseph's Health System in October 2000, and was available to PABDP patients and families to meet their spiritual needs. Ms. Morrow has resigned, and it is hoped that there will be an appropriate replacement soon.

(Activities 5.5-5.7) Assessment and evaluation services by Registered Dietitians, Physical Therapists, and Developmental Specialists were provided as clinically indicated. They were coordinated with clinic visits as much as possible, in order to maximize utilization of patients' time and to avoid unnecessary and burdensome travel.

(Activity 5.8) The 24-hour triage telephone service was established to provide ongoing patient management after regular clinic hours. The phone number was given to patients and families at initial clinic visits and was also on the ID cards provided to each patient. The contact mechanism was as follows: patient phoned service, the hematologist on call made a clinical evaluation, and treatment ensued. This number was accessible to all health care providers, patients, and families.

Objective 6 was to develop a comprehensive continuous care plan from birth through transition into an adult medical home for 90% of the clients referred to the program to be sent back to the primary care physician and care coordinator within 60 days of assessment by: facilitating and maintaining communication among the comprehensive treatment center, primary care physicians, and home health agencies assisting with the care of these children (Activity 6.1); establishing community liaisons (Activity 6.2); and coordinating and supporting a centralized transition program from pediatric/adolescent

care to adult care for children and adolescents (birth to 21 years of age) with sickle cell syndromes and other inherited hematological disorders (Activity 6.3).

*Progress Made:*

(Activity 6.1) PABDP maintained rapid exchange of patient information with each patient's primary care provider, while adhering to confidentiality regulations. The program considers this critical in ensuring continuity of care from the clinic setting to the regional setting.

(Activity 6.2) PABDP concentrated its efforts in establishing and maintaining community liaisons in the 24 counties that the program served.

(Activity 6.3) PABDP staff made initial efforts in this area, most notably hosting a dinner and presentation for area adult hematologists. The speakers for this event were 2 noted experts in the area of transition for sickle cell patients, Dr. Joseph Telfair and Dr. Charles Daeschner. More work is needed in this area. The adult sickle cell patient population needs were the responsibility of the Region I Educator/Counselor for the NC Sickle Cell Syndrome Program.

Objective 7 was to establish a culturally competent and comprehensive resource center by September 30, 2000 by: developing the mechanism for cultural competence (Activity 7.1); and providing training for local care providers (Activity 7.2).

*Progress Made:*

(Activity 7.1) Amy Niemas, MSW attended various workshops and conference topics on cultural diversity, and also had formal and informal training in this topic area. This information was shared with PABDP team members on a case by case basis, as issues pertaining to cultural diversity arose. Cultural competency assessments were maintained

on a yearly basis for the PABDP multidisciplinary team. These evaluations provided ongoing information about perceptions of and abilities to provide culturally competent care. PABDP staff also coordinated and assisted in the creation of a video on cultural competence as it related to hemoglobinopathies. Contracting decisions were made with S & S Video of Asheville, and the video was completed in March 2001.

(Activity 7.2) PABDP staff shared the video with area and state providers. Because direct care staff turnover and general lack of experience in dealing with sickle cell disease are common in Western North Carolina, continued efforts in provider training will be essential in continuing to provide culturally competent care.

Objective 8 was to establish a centralized regional data center to track infants, children and adolescents with sickle cell disease or other inherited hematological disorders by September 30, 2000 by: creating the position of Data Manager to coordinate the collection and recording of appropriate clinical information (Activity 8.1); acquiring the computer hardware and software to coordinate the regional medical record needs and maintain confidentiality of patients followed by physicians throughout Western North Carolina (Activity 8.2); coordinating with the NC Sickle Cell Program and federal agencies to provide requested indicators for the WNC population (Activity 8.3); participating in national and regional sickle cell research studies (Activity 8.4); obtaining parental and patient informed consent with IRB approval prior to any study (Activity 8.5); developing monitoring of the program by the institution's Ethics Committee (Activity 8.6); and developing quarterly monitoring of the program's cost effectiveness and efficiency (Activity 8.7).

*Progress Made:*

(Activities 8.1-8.3) These activities were coordinated by the Research Assistant, Jenean Flanagan, who was initially hired by the state to complete data work for the grant, and who later continued as a private contractor with MSJ.

(Activities 8.4-8.5) The Research Assistant made numerous contacts with other medical centers in the state regarding participation in research and these opportunities were reviewed with Dr. Bottom. The program adopted the national guidelines for the use of hydroxyurea in the treatment of some patients, when clinically indicated.

(Activities 8.6) Dr. Beaty sits on the Ethics Committee for Mission St. Joseph's Health System. He reported directly to this committee regarding any issues related to the Pediatric/Adolescent Blood Disorders Program.

(Activities 8.7) Barbara McLean, Department Director for MSJ Pediatric Outpatient Units, worked with the Mission St. Joseph's Hospital Foundation to maintain accurate financial statements regarding all grant activities.

Objective 9 was to develop satellite clinics within identified areas of the Western North Carolina region, in response to patient population and need by: collecting data to identify concentration areas of patients who are missing appointments due to transportation and related issues (Activity 9.1); establishing the first PABDP satellite clinic by March 2001 (Activity 9.2); and assessing the ongoing efficiency of current clinics and exploring needs for other satellite clinics (Activity 9.3).

*Progress Made:*

(Activity 9.1) PABDP staff collected data on missed appointments, and discovered that a majority of the missed appointments were patients who lived in the Forest

City/Rutherfordton area of Western North Carolina. The major reason for the missed appointments revolved around transportation and related issues. This area of North Carolina is approximately 70 miles from Asheville. The terrain involved in travel can easily extend the travel time to 2 hours, from that area to Asheville. Patients and families responded enthusiastically to the proposed clinic idea.

(Activity 9.2) Susan Maultsby, Project Director, initiated collaboration with Rutherford Pediatrics in regards to the satellite clinic. The first clinic was in February 2001. Due to physician staffing issues, the satellite clinic has not taken place as often as was initially anticipated. However, the PABDP team recognized the clinic as a needed service, and it is hoped that the clinic will operate on a quarterly basis if the staffing issues are resolved.

(Activity 9.3) Proposed areas for clinic expansion have been researched and discussed with Dr. Bottom. Possible sites include Gaston County and/or Catwaba County. These clinics would also operate on a quarterly basis, and would bridge an important gap in patient utilization through the development of these clinics. The clinics' progress would need to be assessed on a quarterly basis.

#### Other Areas of Importance

There are several other areas in which PABDP staff has done extensive work, in addition to the grant objectives discussed. These are:

- A focus on patient and parent involvement in the program; specifically, sending families to national conferences, providing support groups, hosting family events, and working towards patient self-determination/active involvement in treatment

- Collaboration with numerous medical centers, both in North Carolina (Carolinas Medical Center and ECU), and nationally recognized sickle cell centers (Grady Health System)
- Collaboration with community-based sickle cell centers at both the state and national level
- Consistent and active participation on key committees at the state level, including the NC Sickle Cell Syndrome Consortium
- Recruitment and involvement of patients and families from all ethnic backgrounds who are affected by blood disorders
- Coordination of and involvement in regional and state summer/fall camps for patients
- RN/Project Manager and SW certification as Sickle Cell Educators/Counselors through national sickle cell disease certification program
- Development of monthly program report shared with appropriate MSJ and NC Sickle Cell Syndrome Program leadership, to insure timely and accurate communication regarding PABDP activities
- Development of program website and brochure

IV. EVALUATION: Process evaluation and measurable health outcomes analysis have been used throughout the program's development and with completion of objectives. Included are evaluations that promote an efficient and replicable Pediatric/Adolescent Blood Disorders Program, which can serve as a model for other programs.

V. RESULTS/OUTCOMES (POSITIVE & NEGATIVE): PABDP has been fully staffed since October 2000. In just over 2 ½ years' time, nearly all of the original grant objectives have been achieved, and a replicable program model has been developed.

Only a few grant activities were not completely accomplished by the end of the grant period: establishing a linkage with the NC State Newborn Screening Program for identification and follow up regarding newborns and children with an abnormal hemoglobin result (Activity 2.2); coordinating and supporting a transition program (Activity 6.3); participating in national and regional sickle cell research studies (Activity 8.4), and obtaining IRB approval (Activity 8.5). The newborn screening activity (Activity 2.2) was hampered by data sharing and personnel issues at the state level, as previously discussed, and was thus out of the control of PABDP. Beginning work was done on the transition program activity (Activity 6.3), as previously discussed, but more work needs to be done in this area. Research studies (Activities 8.4/8.5) were explored but not implemented. Thus, good faith efforts to complete all of these activities were made by PABDP.

Virtually all grant activities and objectives were implemented during the grant period (with the exceptions noted above). However, the vast majority of these same activities will need to be continuously re-implemented, in order to ensure ongoing culturally competent and comprehensive care. *(Please see Grant Objectives Appendix on Pages 22-23 for breakdown of grant objective status.)*

VI. PUBLICATIONS/PRODUCTS: N/A

VII. DISSEMINATION/UTILIZATION OF RESULTS: The Pediatric/Adolescent Blood Disorders Program (PABDP) is now recognized as a regional referral site for the

NC Sickle Cell Syndrome Program in Region I. The program has participated in the state's data collection process for a number of variables which track service utilization, patient program utilization, inclusion in study-related protocols, and disease-specific acute episodes. These reports have been assessed quarterly and submitted to the NC Sickle Cell Syndrome Program, which is within the state's public health program.

PABDP has continuously worked with the state program to overcome barriers in regards to referrals and newborn screening results.

VIII. FUTURE PLANS/FOLLOWUP: The sickle cell population has been historically underserved and discriminated against, and this grant was an excellent opportunity to initiate needed services to a minority health population. The medical and psychosocial research has demonstrated that this patient population is easily lost to follow-up, due to the nature of chronic disease and to racial barriers. Supportive and consistent staffing (i.e., building trust between staff and families) is recognized as key to ensuring long-term patient compliance with treatment. Providing specific staff members to work with this population also results in a significant decrease in ER visits and hospitalizations, thus improving quality of life, decreasing medical costs, and insuring optimal health status. This idea was clearly supported and endorsed by the writers of the original grant, and was deemed significant enough to include it as a specific objective (Objective 4).

Continuing work clearly needs to be done on an ongoing basis to ensure patient health and access to services. Dr. Beaty and Dr. Bottom have made a commitment to provide ongoing medical care for the patients, which is essential. PABDP has also been notified that it will receive a contract from the NC State Sickle Cell Program to provide services to patients and families after the grant period is over. While the medical piece is

obviously critical, it is important to remember that it is only part of the care model PABDP developed for this patient population. The psychosocial efforts (including community services, case management, etc.) are essential in maintaining patient compliance with medical treatment.

#### IX. TYPE/AMOUNT OF SUPPORT AND RESOURCES NEEDED TO REPLICATE:

The hospital has supported the efforts of this program from its inception. (Included in hospital support have been the following financial resources: Physician Salary – \$55,000; Rent – \$8,100; Telephone – \$3,600; Dues/Books/Subscriptions – \$1,000; and Repairs/Maintenance – \$1,000, for financial support of \$68,700 each of the four years of the program.) In addition, management support has been provided by Barbara McLean, Department Director for Pediatric Outpatient Departments. This support will continue as the program evolves to its position as a part of the State of North Carolina Division of Public Health program for Morbidity and Mortality of Individuals and Families affected by Sickle Cell Disease. This contract began on July 1, 2003 and provides financial support to the program at Mission St. Joseph's in the amount of \$60,000 for the first year, with contract renewable annually. MSJ will hire an RN who will work with staff hematologists/oncologists to provide ongoing medical care, education, and resources for patients with sickle cell disease and their families. This program will work with the State Sickle Cell Coordinator for Western North Carolina (a social worker) to ensure that the sickle cell population has the medical care and the resources needed to cope with their disease. The hospital is providing physician and management leadership, space, and other support needed for the program. This program could also be easily replicated in

another setting, following the MSJ model. Collaboration with regional and state agencies has been instrumental in broadening the scope of the project.

## ANNOTATION

Prior to the inception of this grant, there were no local systems of care for children in Region I – which includes 24 counties and covers more than 8,000 square miles in Western North Carolina – of the NC Sickle Cell Syndrome Program. Goals for the Pediatric/Adolescent Blood Disorders Program included addressing the unmet medical and psychosocial needs of the patients and families involved; improving the health of children living with sickle cell disease and other inherited disorders; increasing the knowledge and understanding of sickle cell disease and other inherited blood disorders in Western North Carolina; and, ensuring continuity of care for all patients in the program. Program activities utilized to achieve these goals included establishing a regional center for early and rapid response to the identification of a newborn with an abnormal hemoglobin; ensuring that these newborns have a health and preventive care plan; collaboration with middle and high school nurse-managed clinics in the region; development of 24-hour comprehensive ambulatory outpatient and inpatient care for patients with sickle cell and other inherited hematologic conditions; establishment of a culturally competent and comprehensive resource center and a centralized regional data center; and, development of satellite clinics within identified areas of the Western North Carolina region. These objectives were met, with a focus on patient and family involvement in the program and through collaboration with numerous medical centers at the state and national level. During the time period the grant covered, a replicable program model was successfully developed.

KEY WORDS cultural sensitivity, family-centered health care, family-centered education, newborn screening, professional education in cultural sensitivity, regional programs, regionalized care, sickle cell disease, patient satisfaction

**APPENDIX A: GRANT OBJECTIVES – STATUS AS OF APRIL 2003**

<b>Activity number</b>	<b>Implemented during grant period</b>	<b>Ongoing work also needed</b>	<b>Initial work done, but needs more in the future</b>	<b>Not implemented during grant period</b>
1.1	X			
1.2	X			
1.3	X			
1.4	X	X		
1.5	X	X		
2.1	X			
2.2			X	
2.3	X	X		
2.4	X	X		
3.1	X			
3.2	X	X		
3.3	X	X		
4.1	X	X		
4.2	X	X		
4.3	X	X		
4.4	X	X		
4.5	X	X		
5.1	X	X		
5.2	X	X		
5.3	X	X		
5.4	X	X		
5.5	X	X		
5.6	X	X		
5.7	X	X		
5.8	X	X		
6.1	X	X		
6.2	X	X		
6.3			X	
7.1	X	X		
7.2	X	X		
8.1	X			
8.2	X			
8.3	X	X		
8.4				X
8.5				X
8.6	X	X		
8.7	X	X		
9.1	X			

9.2	x			
9.3	x	x		

Note: As can be seen in the table above, the vast majority of grant activities and objectives were implemented during the grant period. In order to sustain the program, ongoing work will be required in most of these areas. This is the reason for two boxes being marked for most of the activities.